Pathway 3A: TYA Guidance for Referral of patient Abroad for NHS Proton Beam

Principal Treatment Centre: University College London Hospital
Tumour Type: Proton Beam Therapy

Note: Patients up to and including the age of 18 years should be treated at UCLH. Patients aged 19-24 years should be offered the choice between UCLH or a TYA designated hospital (Pathway 1b).

Suspicion of cancer or cancer diagnosis (incidental/A&E/GP/Drop in)
- Diagnosis
  - Diagnostics
  - Patients will be identified as suitable for proton beam therapy by the site specific MDTs at GOSH/UCLH.
  - Staging test specific to their tumour will be performed as appropriate.

Treatment planning
- Discussion at UCLH at
  1. National proton beam therapy reference panel (13-24 years)
  2. Agreed Treatment Plan + fertility assessment
  3. Treatment plan discussed and agreed at TYA MDT
  4. Allocated TYA Key Worker and other TYA AHPs for holistic care
  5. Registration to NWCIS (14-24yrs) by TYA MDT

TYA Team involvement
- Rapid re-entry to diagnostic MDT for relapse
- Treatment plan initiated by named oncologist:
  - Radiotherapy
    - Dr Y Chang
    - Dr N Fersht
    - Dr M Gaze
    - Dr A Cassoni

Post treatment
- End of First line treatment review
- End of treatment summary by 12 weeks by named oncologist or keyworker
- No further active treatment available refer to palliative care (Dr Caroline Stirling and palliative care team)

Follow-up
- Follow-up will be with the referring clinical oncologist.
- Access into the LTFU clinic as required

TYA Team Supportive Model of Care
- Holistic Needs Assessment (HNA) first 4 weeks
- Patient / carer support
- Multi Disciplinary Team support as required/requested
- Family Support Network
- End of Treatment summary 12 weeks post completion of treatment

Team Members
- Consultant Clinician
- CNS (Key Worker)
- Social Workers
- Youth Support Coordinator
- Specialist psycho-oncology team
- Allied Health Care
- Late Effects Team

Transition
- Referral into the UCLH TYA service at age 13 years
- Referral into the adult TYA team at/around 20th birthday
- TYA MDT patients aged 24+ transition to adult services

Abbreviations Key:
- MDT: Multi Disciplinary Team
- NWCIS: North West Cancer Intelligence Service
- LTFU: Long Term Follow Up
- CNS: Clinical Nurse Specialist
- TYA: Teenagers and Young Adults
### Pathway 3A: TYA Guidance for Referral of patient Abroad for NHS Proton Beam Diagnostics

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<td><strong>Patients</strong>&lt;br&gt;will be identified as&lt;br&gt; suitable for proton beam therapy by&lt;br&gt; the site specific MDTs at GOSH/UCLH.&lt;br&gt; Staging test specific to their tumour will be performed at GSOH/UCLH as appropriate.</td>
<td><strong>SITE SPECIFIC MDT</strong>&lt;br&gt; <em>National Proton Beam Reference Panel</em>&lt;br&gt; Location: Nationwide panel, coordinated via Leeds&lt;br&gt; Time: Ad hoc&lt;br&gt; Lead Clinician: Adrian Crellin&lt;br&gt; Coordinator: Angelina&lt;br&gt; Phone: 0113 2068602&lt;br&gt; Email: <a href="mailto:leadsth-tr.protonNCG@nhs.net">leadsth-tr.protonNCG@nhs.net</a></td>
<td><strong>TYA MDT</strong>&lt;br&gt; Location: UCLH&lt;br&gt; Time: Wednesdays, 15:00-17:00&lt;br&gt; Lead Clinician: Dr Rachael Hough&lt;br&gt; Coordinator: Maria Jose&lt;br&gt; Phone: 020 3447 1858&lt;br&gt; Email: <a href="mailto:ucl-tr.TYAMDT@nhs.net">ucl-tr.TYAMDT@nhs.net</a>&lt;br&gt; 1. All TYA patients will be discussed in the TYA MDT.&lt;br&gt; 2. The TYA MDT will review the treatment plan made by the site specific MDT and promote access to clinical trials wherever possible&lt;br&gt; 3. The TYA MDT will review the support network around each individual patient, identify any psychosocial issues and how these will be addressed.&lt;br&gt; 4. The TYA MDT will ensure that a keyworker and other allied health professionals are identified for each patient&lt;br&gt; 5. The agreements reached between the site specific MDT and TYA MDT will be documented</td>
<td><strong>End of treatment review and clinic with patients clinical oncologist</strong>&lt;br&gt; A comprehensive end of treatment summary is provided by the treating proton centre in the USA. These are scanned into the patients electronic record on CDR.&lt;br&gt; Initial and long-term follow up will be by the clinical oncologist and keyworker in the radiotherapy clinic</td>
<td><strong>Introduce TYA service to patient (by post or face to face assessment )</strong>&lt;br&gt; Discuss at TYA MDT allocate key worker&lt;br&gt; Holistic Needs Assessment (HNA) done within 4 weeks of referral to team&lt;br&gt; Support from TYA MDT members throughout the patients treatment pathway according to patient wishes&lt;br&gt; Information and support patient and carer (TYA team) supporting age appropriate care&lt;br&gt; Invite to end of treatment group/meet face to face for after treatment review&lt;br&gt; Family support network</td>
<td><strong>Transition into the TYA service will be around the 13th birthday at a time appropriate in the patient’s treatment. These patients will usually be transitioned from GOSH or the paediatric oncology team at UCLH.</strong>&lt;br&gt; Within the TYA service, transition from the teenage to young adult teams will occur at or around the 20th birthday.&lt;br&gt; Full transition into adult facilities, but with the same clinical team, will occur at or around the 25th birthday.&lt;br&gt; Note: transition will be planned for and discussed with patients well in advance. Transition at a time of crisis eg relapse, intensive chemotherapy will be avoided wherever possible. Transition will be facilitated by the keyworkers</td>
<td><strong>Follow-up will be with the referring clinical oncologist. Frequency of visits and surveillance scans determined by disease indication. Access into the LTFU clinic as required</strong></td>
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### IT Systems

| **Data Register with**<br>NWCIS<br>TYA DATA BASE | **Note:** Emergency or urgent treatment should not be delayed to allow discussion at the TYA MDT |

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